



Coming of Age

My Journey with COPD: Advocacy and Empowerment

by Edna Fiore

Dr. Thomas L. Petty began a concerted effort to promote COPD awareness and advocacy in the mid 1990s. His initial emphasis was on the education of the professional community about the importance of spirometry testing as a routine part of medical examinations and the education of both the general public and professional community about chronic obstructive pulmonary disease. His initial efforts culminated in the first U.S. COPD Coalition National Conference in 2003. I had the privilege of working closely with Dr. Tom beginning in 2004. My journey in the cause for COPD awareness has been exciting and rewarding in innumerable ways.

My introduction to the respiratory world began in 1995 when I retired and moved from sea level in Newport, OR, to join my family in Conifer, CO, at an elevation of 8,500 feet. I had been spending vacations and holidays in Conifer for several years without any noticeable breathing problems, but within a short time I began to notice a little shortness of breath. An advertisement in the *Rocky Mountain News* led me to Colorado Pulmonary Associates (CPA) and Dr. Tom Petty's research assistant, Wayne Silvers. A lifelong history of episodic asthma, a number of bouts with pneumonia, and a family history of respiratory problems combined with my status as a former smoker qualified me for a series of studies at CPA.

Colorado proved to be the right place for someone with COPD. Historically, Colorado has been a national and world leader for the diagnosis and treatment of lung disease. From 1840 to 1920 it was considered the number one destination for people suffering from asthma and tuberculosis; as much as 60% of Colorado's early settlers migrated to the area seeking help for their respiratory ailments. National Jewish Health began serv-

ing respiratory patients in 1899 and has the distinction of being named the number one respiratory hospital by *U.S. News & World Report* for 11 consecutive years.

In 1998 I moved to Lakewood, a Denver suburb, in order to be closer to the site of the research studies and resources for my own research as historian for the Town of Morrison and the Lariat Loop Heritage Alliance. I registered for research studies at National Jewish in 1999 where I was first introduced to tiotropium, a medication that I considered a "wonder drug." My stamina and endurance were easily doubled by it. My FEV₁ was hovering around 30% before I entered the study. At the conclusion of another tiotropium study in 2001, my FEV₁ had improved to 45%.

I later participated in the pulmonary rehabilitation program at Exempla Lutheran in Wheat Ridge, CO, in 2001 where I was introduced by Brenda Crowe, CRT, to the world of collaborative self-management and the importance of a pulse oximeter.

My personal odyssey with oxygen began in earnest in 2004 when I was prescribed oxygen for sleep and exertion. In 2006 two exacerbations and a lung abscess drastically reduced my lung capacity; and although I still maintained an FEV₁ of 40%, my daytime oxygen saturation had slowly declined to just about 90%, so I was prescribed two liters of oxygen 24/7.

about the author...



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The path to COPD awareness and advocacy

I first discovered the larger COPD community in 2002 when I was searching the Internet for a source in Europe where I could obtain Spiriva. I clicked on www.emphysema.net and discovered the Emphysema Foundation For Our Right To Survive (EFFORTS). EFFORTS opened a whole new world of information and support and started me on the path

to COPD awareness and advocacy. I learned that EFFORTS held rallies in Washington, DC, in 2000, 2001, and 2002 that brought COPD awareness to both legislative and public attention.

EFFORTS afforded me a “crash course” in COPD awareness, and within a very short time I was appointed EFFORTS state leader for Colorado. My first endeavor, with the help of Cindy Liverance, vice-president of the American Lung Association of Colorado, was an EFFORTS “Gathering” featuring a program about COPD research and general information at Lutheran Hospital in June of 2003. The first U.S. COPD Coalition National Conference, already in the planning stages and set to be held in Arlington, VA, in conjunction with the second World COPD Day in November of 2003, was the next EFFORTS endeavor. I immediately made plans to attend.

The encouragement and enthusiasm generated by this conference resulted in the first Colorado COPD Conference in 2005, which was planned by the Colorado COPD Network along with the National Emphysema/COPD Association. The theme was “COPD: Living the Colorado High Life.” This conference has since become an annual event and in 2009 was officially designated the “Thomas L. Petty MD Moving Mountains Lung Health Conference.”

Another result of the U.S. COPD Coalition Conference (which includes the AARC) along with the EFFORTS DC rallies and support by the ATS, American College of Chest Physicians, and the American Lung Association, was the formation of the Congressional COPD Caucus in 2004 by Sen. Mike Crapo (ID). Reps. Cliff Stearns (FL) and John

Lewis (GA), and Sen. Blanche Lincoln (AR) joined Sen. Crapo as caucus co-chairs.

The Congressional COPD Caucus gave the COPD community a public platform in Congress to bring attention to critical issues that have been identified by the U.S. COPD Coalition and the patient and professional COPD communities. The first issue addressed by the caucus was the difficulty of flying with supplementary oxygen. Their efforts, along with other patient groups including National Home Oxygen Patients Association, National Emphysema COPD Association, and COPD-ALERT, resulted in the Federal Aviation Administration ruling on Aug. 11, 2005, permitting the use of approved portable oxygen concentrators (POCs) on the airlines and the Department of Transportation ruling that obligated airlines to permit the use of FAA-certified POCs in 2009.

The year 2006 was a “red letter” year for COPD advocacy and awareness as Bartolome R. Celli, MD, presented his paper, “Chronic Obstructive Pulmonary Disease: From Unjustified Nihilism to Evidence-based Optimism,” at the May American Thoracic Society (ATS) Conference. This landmark treatise worked wonders in removing the “blame the victim” smoking stigma and placing COPD, the fourth leading cause of death, on the same footing as other major health issues.

Another milestone in 2006 was the creation of the Colorado COPD Coalition, which brought together a diverse group of stakeholders from all over the state, including health professionals, patients, research scientists, industry representatives, state officials, and caregivers. The coalition held a COPD Summit in May, and under the guidance of Keith Breese of the American Lung Association prepared and began implementation of the Colorado State COPD Plan in 2006/2007.

The “Colorado COPD Surveillance Report” was developed and disseminated in 2007. Keith represented Colorado at the first State COPD Coalition and presented the Colorado State COPD Plan at the U.S. COPD Coalition meeting during the 2007 CHEST Conference. This plan has subsequently served as the prototype for the formation of many other state COPD coalitions.

Colorado Society for Respiratory Care (CSRC) inaugurated the first patient chapter and speakers bureau in 2007, bringing representatives from patient support groups and professionals together for educational and awareness activities.

The ATS and the Forum of International Respiratory Societies’ “2010: The Year of the Lung” public awareness campaign officially launched on Dec. 5, 2009, at the 40th Union World Conference on Lung Health in Cancun, Mexico. On Jan. 15, 2010, the American Lung Association of Colorado, the University of Colorado, and Colorado COPD



Edna Fiore (seated) participated in the 2010 AARC PACT Lobby Days in Washington, DC. Standing (from left) are Allen Wentworth, Leigh Otto, and Sen. Michael Bennet (CO).

Connection presented the first “2010: The Year of the Lung” event with a “Breathing Matters: Living Well with Chronic Lung Disease” forum at the Native American Health Center on the Anschutz campus of the University of Colorado.

The capstone of my adventures in COPD advocacy occurred when I had the privilege of serving along with Allen Wentworth, RRT, and Leigh Otto, MEd, RRT, as a member of the CSRC Political Advocacy Contact Team at AARC’s DC Lobby Days in 2009 and 2010. This was really an eye-opening opportunity to experience firsthand the influence that individuals and organizations really do have on the legislative actions of Congress.

Impacting respiratory issues at home and nationally

My involvement in COPD awareness and advocacy provides a way for me to make a positive impact on my own respiratory issues and on the lung health of many people who come away from the doctor’s office with a diagnosis of COPD. Thanks to Dr. Tom’s legacy of long-term oxygen therapy and a comprehensive collaborative care program,

I have been able to maintain an FEV₁ between 35–40%. I consider myself singularly blessed with the privilege of representing and serving all of the patients, caregivers, and health care providers who deal with the day-to-day problems of living with a chronic lung disease.

What’s next?

A primary focus of my current activities is passage of H.R. 941, the Medicare Respiratory Therapy Initiative, and the introduction of a companion bill in the Senate. Also, as secretary of the Colorado COPD Connection, an organization of patients, RTs, and industry representatives, I edit a monthly eNewsletter and participate in the planning for the 8th annual Thomas L. Petty MD Moving Mountains Lung Health Conference.

A strong alliance of RTs and patient activists is vital for effective COPD education in both the public and professional sectors. The Colorado COPD Connection is recruiting respiratory therapists throughout Colorado to bring COPD information and education to all areas of the state, particularly the rural areas. ■